

Using Silence to Hear the Voices of the AAPI Community in Autism Diagnosis and Treatment

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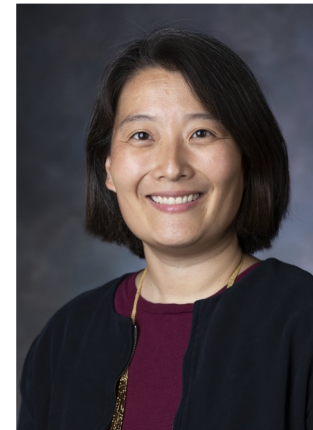
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Learning Objectives

- Understand some of the cultural complexities of working with AAPI families in clinical settings
- Describe cultural considerations for the IDD/ASD assessment process
- Describe cultural considerations for providing treatment recommendations



“Silence is golden.”

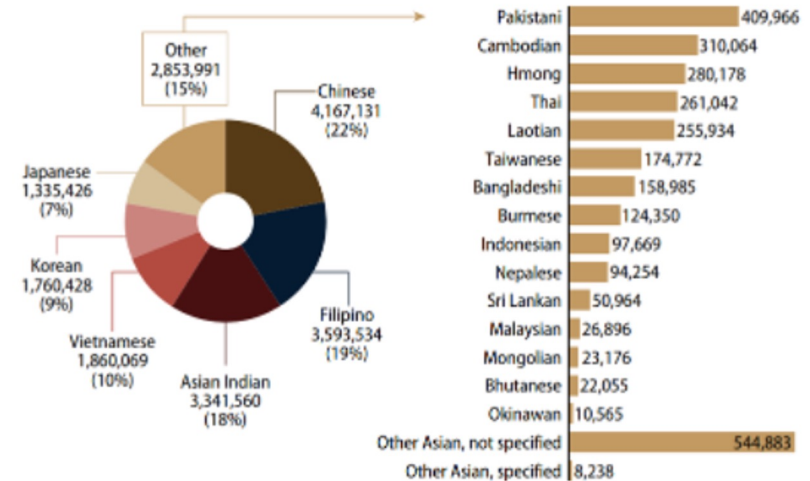


Cultural Complexities of Working with AAPI Families

Who makes up the AAPI community? (1 / 3)

- 6% of the US population (19.9 million people) identify as Asian (2020, US Census)
- Heterogeneous community
- 74.4% speak a language other than English
- 33.2% with limited English proficiency

Ethnicity and national origin of the Asian American population, 2012



Source: Bureau of the Census, "Asian alone or in any combination by selected groups, 2012," available at http://factfinder2.census.gov/bkmk/table/1.0/en/ACS/12_1YR/002010 (last accessed March 2014).

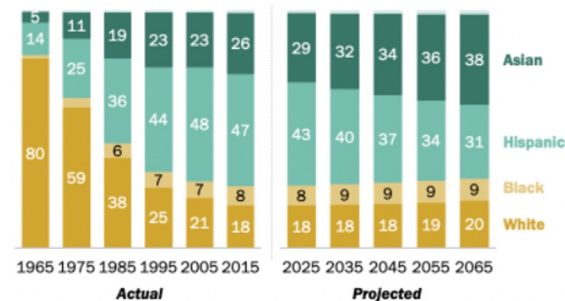
(aapidata.com, Asian Pacific Institute)

Who makes up the AAPI community? (2/3)

- 27% live in multigenerational homes
- 66.3% are born outside the US

Asians projected to become the largest immigrant group in the U.S., surpassing Hispanics

% of immigrant population



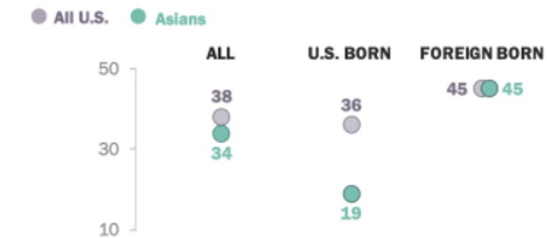
Note: White, Black and Asian populations include those who report being only one race and are not Hispanic. Asians include Pacific Islanders. Hispanics are of any race. Other races shown but not labeled.

Source: Pew Research Center estimates for 1965-2015 based on adjusted census data; Pew Research Center projections for 2025-2065.

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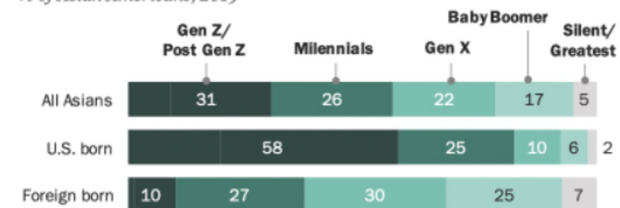
U.S.-born Asians are significantly younger than their foreign-born counterparts ...

Median age, 2019



... and nearly 60% are members of Gen Z or younger

% of Asian Americans, 2019



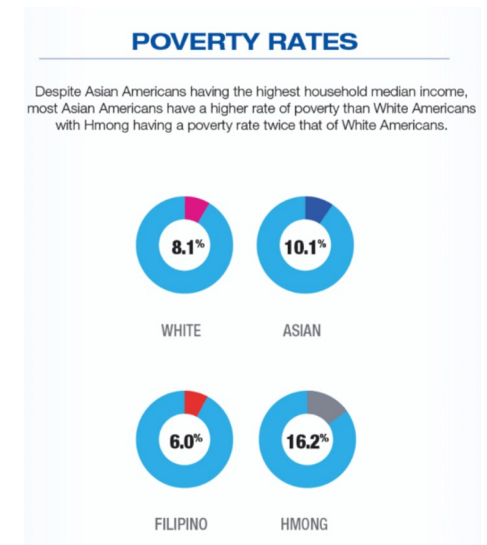
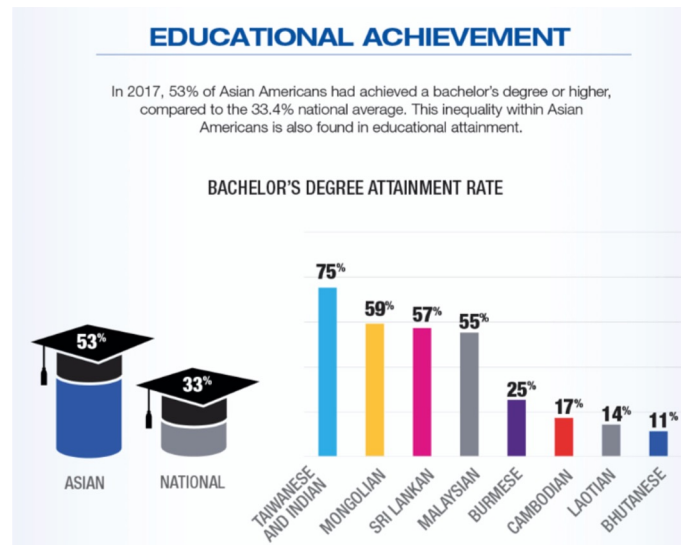
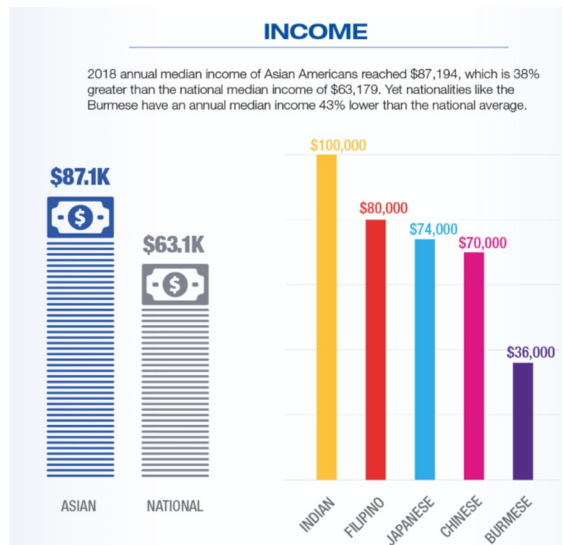
*No chronological endpoint has been set for Gen Z. For this analysis, Generation Z is defined as those ages 7 to 22 in 2019.

Note: Figures for all Asians include mixed-race and mixed-group populations, regardless of Hispanic origin. Figures may not add up to 100% due to rounding.

Source: Pew Research Center analysis of 2017-2019 American Community Survey (IPUMS).

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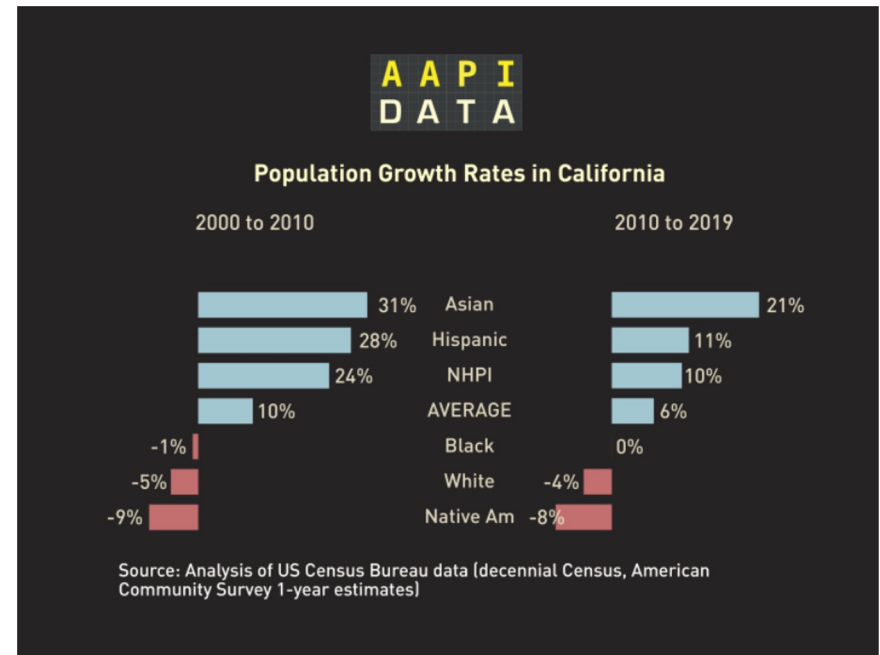
Who makes up the AAPI community? (3/3)



(National Community Reinvestment Coalition)

AAPI in California

- Fastest growing minority population
- CA counties with highest AAPI populations (aapidata, 2018)
 - Los Angeles (14%)
 - Santa Clara (34%)
 - Orange (19%)
- 9% lack health insurance
- 12% live in poverty



(aapidata.com, 2019)

AAPI Students in California

AAPI student demographics in 2019-20



12% of the state's 6.2 million K-12 students are part of the AAPI community



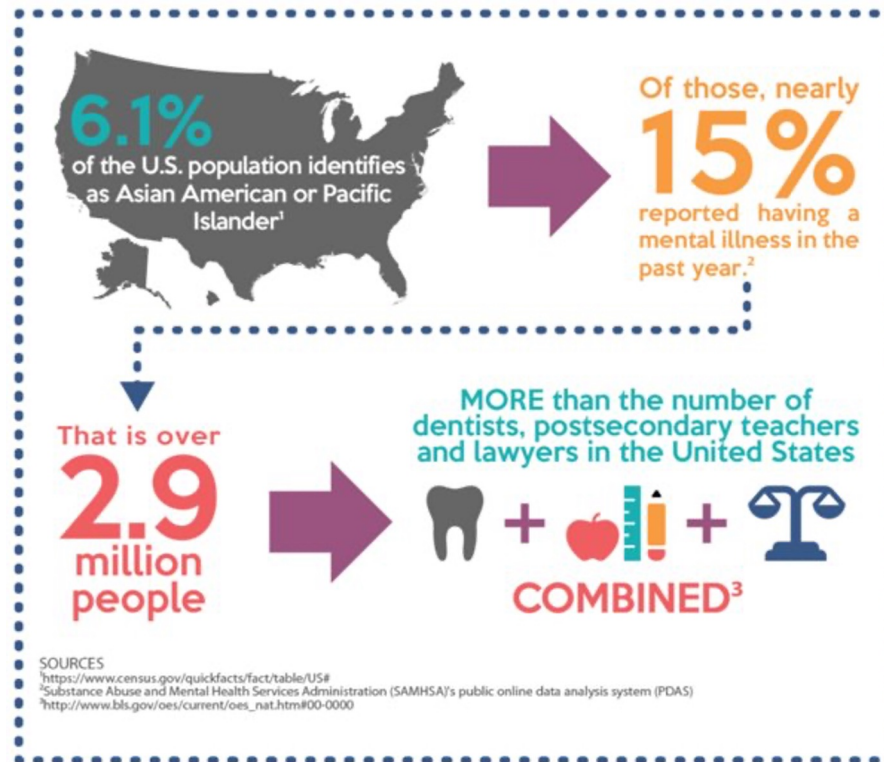
88% of local educational agencies had Asian American, Filipino and Pacific Islander students enrolled

- AAPI students are **identified at significantly lower rates** than any other ethnic/racial group in CA (Anderson, 2021)
 - 11% statewide identification of special needs
 - 6% AAPI

- Of the 12 most commonly spoken languages (in CA school system)
 - Chinese (2)
 - Vietnamese (3)
 - Korean (4)
 - Tagalog (7)
 - Japanese (12)

(aapidata.com, 2019; CSBA, 2019)

AAPI and Mental Health (1/3)



AAPI and Mental Health (2/3)

General mental health:

- Low help seeking rates
- <25% AAPI adults received mental health treatment in 2019 (SAMSHA, 2019)
- Suicide is the leading cause of death for AAPI youth ages 15-24 (US Department of Health and Human Services, 2021)
- High rates of PTSD in SE Asian refugees (NIH, 2006)

In developmental disabilities:

- Minority populations may be at higher risk of underdiagnosis or later diagnosis of ASD (Imm et al., 2019, Magana et al., 2012, Zeleke et al., 2019)
 - Highest disparities seen with Black and Latinx families

AAPI and Mental Health (3/3)

- **Shame and stigma may lead to underdiagnosis or concealment**
 - Korea: Clinicians may designate another diagnosis instead of autism to avoid social judgment (Freeth et al., 2014)
 - Families may be shunned or individuals rejected for marriage due to family member's diagnosis (Kang-Yi, 2018)
- **No racial/ethnic differences in behavioral challenges, conduct problems or sleep disturbances in children diagnosed with ASD** (Quebles et al., 2020)
 - White children more likely to receive psychotropic medications
 - AAPI children had lowest rates of medication use for behavioral challenges compared to non-Hispanic White, Latinx, Black, and multiracial groups



Question: Barriers to Care

When working with AAPI patients and families,
what barriers to care have you encountered in your clinical work?

Barriers to Care (1/2)

- **Translation of concepts across cultures**
 - Concept of autism in Somali (personal interview, 2020; Ellen Selman et al., 2018)
 - Māori: “takiwātanga” = “in his/her own time and space”
 - What does a family understand in the conversation?
- **Family understanding the autism diagnosis**
 - May conclude environmental, social, or familial influences contributed to autism
 - Shame and guilt at perceived failings as a parent
- **Help seeking minority families report feeling invisible and unheard**
(Stahmer et al., 2019)
 - Lack of access to interpreters in preferred language
 - Dismissal/misattribution of parent concerns
 - Unfamiliarity with service system and how to access



Barriers to Care (2/2)

- **Uncertainties with advocacy process**
 - May feel discordant with cultural values
 - Vulnerability to speak out due to immigration status
 - May require advocacy in a language they are not comfortable speaking
 - Lack of familiarity with special education “vocabulary”

AAPI Community Takeaways

- **Not a monolith**
 - Consisting of more than 50 ethnic groups.
 - Asia broadly speaking, is home to many different religions, faiths, cultures and languages.
- **Danger of the model minority myth**
 - Minimizes the variability that we see across AAPI subgroups
 - Creates social pressure to conform to societal expectations - may decrease help-seeking behaviors in AAPI community



Cultural Considerations

- Look at culture broadly
- Explore family/child's "social location" and barriers that may be wrapped around the family's social location.

Cultural Considerations:

- | | |
|--------------------------------|---------------------------------------|
| ❖ <i>Ethnicity</i> | ❖ <i>Spirituality / Religion</i> |
| ❖ <i>Race</i> | ❖ <i>Literacy Level</i> |
| ❖ <i>Country of Origin</i> | ❖ <i>Sexual Orientation</i> |
| ❖ <i>Gender</i> | ❖ <i>Employment</i> |
| ❖ <i>Age</i> | ❖ <i>Geographic Location</i> |
| ❖ <i>Socio-economic Status</i> | ❖ <i>Physical Ability/Limitations</i> |
| ❖ <i>Primary Language</i> | ❖ <i>Immigration Status</i> |
| ❖ <i>English Proficiency</i> | ❖ <i>Criminal Justice Involvement</i> |
| | ❖ <i>Political Climate</i> |



Consider the Context



- What may be historical factors that may impact the individual, family, or community?
- What are the power and privilege dynamics?
- What are the different types of identity that an individual may identify with (intersectionality)?

(Clauss-Ehlers et al., 2019)

Cultural Competemility

- Synergistic relationship between competence and humility (Campinha-Bacote, 2019)
- Make room for family's cultural differences in parenting styles
- Be aware of different views on teaching self help skills
- Literacy concerns
- Take the time in translating important terms
- Use the terms that family prefers



Cultural Considerations in Clinical Settings

- Practice family-centered care: When possible, allow for a longer intake appointment(s)
- Use interpreters: Confirm the availability of an interpreter (when needed), even if one parent is fluent in English.
- Take a learner stance: Do the background work & be open and humble as you talk with families
- Practice Cultural Competemility: Cultural competemilty (Bacote, 2019) represents an integration of cultural competence and cultural humility.



Cultural Considerations During Intake

- **Example intake questions to incorporate cultural competemility**

- Identify family's level of acculturation and sensitivity to documentation status.
- How long has your family been living in the USA?
- What brought you and your family to the USA?
- What are the languages used at home?
- How would you identify your culture, religion, and race in your own words?
- What are cultural considerations that you would like for us to keep in mind?
- What do family roles look like within your family system?
- Have there been any barriers in accessing/understanding care? If so, let us talk about those barriers and possible ways that I can support you.
- Are there any specific practices or restrictions you would like for us to know about while we are providing care?
- Has anything prevented you from getting the help you need?

Case Study

- ***Family dynamic:*** Amir lives with his mother, father, two older sisters (10 and 12) and his paternal grandparents. Amir's grandparents and older sister play an integral role as caregivers along with his parents.
- ***Patient and family background :*** Amir is a five-year-old Nepalese male. Amir and his family moved here as refugees from Bhutan three years ago. The primary language for his parents and grandparents is Nepali; they are not fluent in English. Amir's older siblings are fluent in both English and Nepali.
- ***Presenting concerns :*** Family's area of concern centers primarily around Amir's speech delay. The referral from pediatrician indicates concerns for possible autism spectrum disorder.
- ***Education :*** Amir attends special needs preschool and has an IEP (Individual Education Plan). His family is unaware of what services Amir is receiving at school. He is not receiving any other services or treatments at this time.

ECLECTIC Framework (Fujii, 2018)

- Cognition does not develop in a vacuum
- Cognitive assessment is a Western convention with its own assumptions, values, and expectations
- Necessity of knowing the cultural context to understand the individual
- Use an ethnorelative perspective

E	Education
C	Culture and Acculturation
L	Language spoken & English Proficiency
E	Economic issues
C	Communication Style
T	Testing Situation
I	Intelligence concept
C	Context of Immigration

Case Study: Intake Considerations

- **Explain assessment process with family and their goals** - Amir's family seems to be confused by the assessment process
- **Cultural Competemility** - Competence while also showing humility
- **Check understanding of vocabulary** - Clarify with interpreter how words are being communicated to Amir's family. Identify how Autism is being described to avoid miscommunication
- **Social Location** - Identify factors within Amir and his family's social location
- **Identify family roles** - Amir's family consists of multigenerational caregiver roles
- **Reassure and normalize intake questions** - All families are asked the same questions
- **Reiterate that everything discussed is confidential** - Amir's family may be worried about their small community and information being shared



Assessment Process

Cultural Considerations for Assessment (1 / 3)

- Create the assessment battery (Stoll et al., 2021)
 - Use established best practices and be aware of standardization samples and norms!
 - Integrate data from multiple sources and informants
 - Use clinical judgment
- Acknowledge potential cultural differences, values, and expectations (Perepa, 2014)

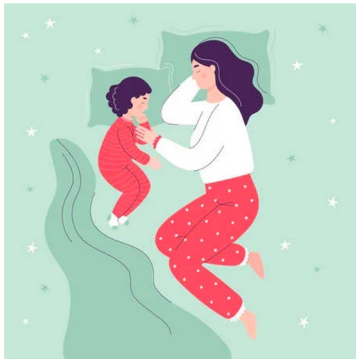
Cultural Considerations for Assessment (2/3)

- ASD assessment and behavioral observations
 - Broad domains are found globally
 - Differences in symptom manifestation may exist (Leeuw et al., 2020)
 - Cultural influence on social communication and interaction skills
 - Limited research on potential ethnic differences on restricted and repetitive behaviors



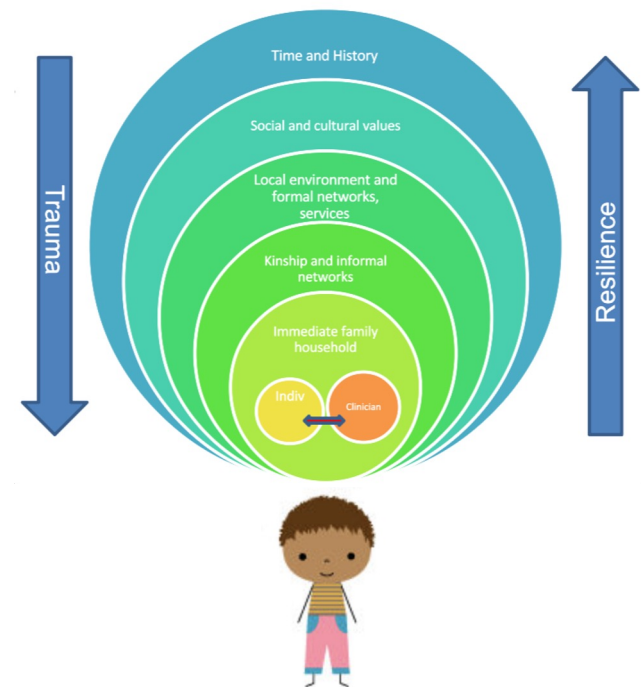
Cultural Considerations for Assessment (3/3)

- Developmental and adaptive assessment
 - Most developmental milestones met at similar ages, except self-help skills (Ertem et al., 2018)
 - No opportunity ≠ delayed
- Note cultural adaptations and interpretations in report



Case Study: Assessment Considerations

- ASD assessment battery: best practices
 - Direct observations: ADOS (BOSA), CARS-2
 - Indirect: ADI-R, thorough developmental history
- Adaptive behavior
 - ABAS, Vineland-3
- Interpretations
 - Make note of cultural differences and any adaptations made to measures
 - De-emphasize scores and interpret through cultural lens
 - Use ECLECTIC model → Amir's exposure to learning opportunities, cultural differences and expectations for behaviors, languages used in home





Treatment Recommendations

Cultural Considerations for Recommendations

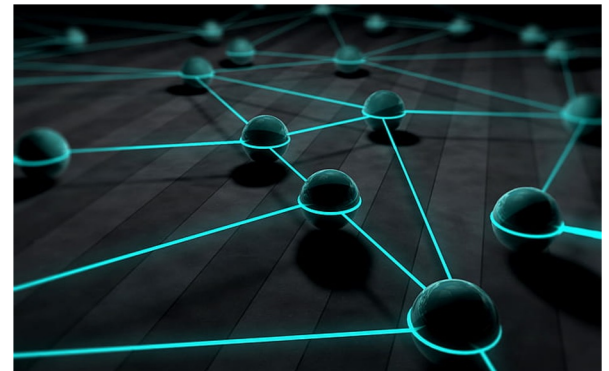
- Enhance clinical care
 - Think beyond the traditional feedback session
 - Select treatment recommendations to share with family
 - Teach how to navigate educational and care systems
- Increase AAPI family access to information
 - Provide high quality interpreter services
 - Translation of written materials



(Sakai et al., 2019; Stahmer et al., 2019)

Cultural Considerations for Recommendations

- Multilevel education and community supports about developmental disabilities
 - General education opportunities for the AAPI communities
 - Create opportunities for shared connections
 - Collaborations with primary care colleagues
- Comprehensive care coordination
 - Take time to explain the service system of care in autism
 - Creative linkages to help families access community service systems
 - Model self-advocacy skills with families





Case Study: Treatment Recommendations

- Addressing language barriers
 - Care coordination
 - Access to interpreters
- Listening to what Amir's family understands about the diagnosis
 - Validating family's fears
 - Providing education
- Linking to parenting education groups about autism



Conclusions



Potential Barriers

- Limited time
- Lack of wrap-around services
- Access to care issues (limited number of providers, inability to follow up with families regularly, immigration status, insurance)
- Long wait lists
- Health literacy - limited information and services in preferred language

Final Considerations

- Adhere to *multicultural/ethnorelative framework*
- Maintain *cultural competimility* - aspirational
- Commit to create a *cultural conversation as an integrated part* of assessment and treatment
- Recommendations to *improve system of care* (Sakai et al., 2019)
 - Support communication
 - Cultural sensitivity
 - Care coordination programming

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Thank you!

Questions?



Case Study

Amir is a five-year-old Nepalese male who presented with a speech delay. He lives with his parents, two older sisters (10 and 12), and his paternal grandparents. Amir and his family moved here as refugees from Bhutan three years ago. Primary language for his parents and grandparents is Nepali; they are not fluent in English. Amir's older siblings communicate in both Nepali and English at home.

Amir attends a special needs preschool; however, his family is unaware of what services he is receiving. They have not had much communication with the school. Amir is not currently receiving any other services or treatments.

At arrival, his family requests for reassurance that their appointment will be covered through their health benefits. Amir, his parents, his older sister, and grandfather, are accompanied by a family friend who assisted with transportation, are present for the appointment. Although an interpreter is present, Aria interprets for the family with some support from the interpreter.

Family reports primary concern of speech delay. Amir has under ten words in his vocabulary that he uses spontaneously and with function, however is often observed echoing others. His expressed words are in English. They report that he does not respond to directions in English or Nepali. His family is confused and unsure of the purpose of the appointment. They request assistance in "teaching Amir how to use his words."

Amir's family shared a report that was provided by the school. Unable to read English, the family is unaware of what the documents contain. The paperwork confirms that Amir has an IEP under an educational diagnosis of autism spectrum disorder. His school identifies concerns with speech, observations of hand flapping, walking on his tip toes, along with isolating himself from peers.

His family's primary focus is on speech and requests help in language development. His school is requesting a formal assessment for diagnostic clarification. Clinicians consider possible paths in navigating appointments with this family.